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# 'If you can't help me, so help me God I will cut it off myself' The experience of living with knee pain: A qualitative meta-synthesis.

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**‘If you can’t help me, so help me God I will cut it off myself…’ The experience of living with knee pain: A qualitative meta-synthesis.**

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## ABSTRACT

### Objective

To identify and explore the feelings and experiences of people living with knee pain as a precursor to exploring how this might contribute to improved care in the future.

### Design

The qualitative meta-synthesis was undertaken in three parts 1) a systematic search of the literature, 2) a critical appraisal of the relevant studies and 3) meta-aggregation of the findings from the selected studies. A qualitative meta-synthesis is a process that enables researchers to answer a specific research question by combining and summarising a variety of qualitative sources. This was undertaken using a contextualist approach which acknowledges different realities exist but tries to determine an underlying 'truth'.

### Setting

The participants from the selected studies were from a range of settings and ethnic groups, and cultural backgrounds.

### Participants

There were nine articles included in the meta-synthesis. Articles focused on the experiences of surgery, return to sport, or other aspects of care were excluded.

### Results

No articles were excluded following critical appraisal. Eleven categories were identified from 55 findings which resulted in two synthesised findings being identified: Knee pain affects every aspect of life and Searching for the best way forward.

**Limitations**

Articles were largely limited to older adults living with osteoarthritis. Many of the findings did not report demographic data. Only English language studies were included.

**Conclusion**

Many people living with knee pain struggle to adapt to living with knee pain and this is often exacerbated by a lack of knowledge and available information to help them plan for the future.

**PROSPERO NO:** CRD42017070227

**CONTRIBUTION OF THE PAPER**

- **This is the first meta synthesis exploring the lived experience of people with knee pain.**
- **This review emphasises the wide-ranging effect of knee pain on peoples' lives.**
- **This study suggests the need for effective and appropriate education to better support people living with knee pain.**

**Key Words:** Knee pain; Qualitative; Osteoarthritis; Experience; Synthesis; Psychosocial.

## ConQual Summary of findings

Review Title: ‘If you can’t help me, so help me God I will cut it off myself…’ The experience of living with knee pain: A qualitative meta-synthesis.

Population: People living with knee pain

Phenomena of interest: The lived experience of knee pain

Context: Any person from across the world living with knee pain.

| **Synthesised Finding** | **Type of Research** | **Dependability** | **Credibility** | **ConQual Score** |
|---|---|---|---|---|
| Knee pain affects every aspect of life | Qualitative | Downgrade 2 levels * | Downgrade 1 level ** | Very Low |
| Searching for the best way forward | Qualitative | Downgrade 2 levels * | Downgrade 1 level ** | Very Low |

* Downgraded two levels due to across the included primary studies (None of the studies had a statement locating the researcher, no acknowledgement of their influence on the research. Most of the studies did not identify a research methodology).

** Downgraded one level due to a mix of unequivocal and credible findings.

## INTRODUCTION

Knee pain is estimated to affect 25% of the adult population on a frequent basis, with osteoarthritis being the most common cause in people over 50 [1]. This has placed increasing strain on all sectors of healthcare as people with knee pain present in ever increasing numbers. In the USA the number of total knee replacements performed increased by 134% between 1999 and 2008 costing over $9 billion [2]. It has been estimated that, even prior to this increase in volume costs of caring for people with osteoarthritis, this accounted for 1- 2.5% of gross national product in the western world [3]. In addition to the financial costs, osteoarthritis has been shown to have a marked effect on Quality of Life (QoL), with QoL decreasing with increasing pain and decreasing physical function [4]. This is often related to reduced levels of mobility and ability to perform Activities of Daily Living [4].

Over the last 10 years there have been numerous high profile evidence-based programmes to manage knee pain more effectively [5]. Despite these efforts, and the increasing evidence base developing for many knee conditions (Osteoarthritis[6], Patellofemoral pain[7,8], Anterior cruciate rehabilitation[9]), there are patients who do not improve despite receiving the current best practice.

Evidence based practice as defined by Sackett [10], and refined by Howick [11], emphasises the importance of patients own beliefs and experiences in the application of evidence base. Awareness of this has led to improved care in low back pain. An increasing awareness of the psychosocial effects of the condition has helped to drive effective management of other musculoskeletal conditions [12,13]. Approaches, such as stratification of patients based on psychological assessment [14], have shown improved management across both primary and secondary care

for people with low back pain [13,14]. There are tools in development exploring whether this approach can be replicated for other conditions [15]. The psychosocial aspect of care has yet to be fully explored in people living with knee pain. It may be that a greater awareness of the lived experience of knee pain may result in better treatment outcomes. In order to determine this, it is first necessary to identify people's experience and feelings of living with knee pain.

The aim of this paper was to explore the feelings and experiences of people living with knee pain as a precursor to exploring how this knowledge might contribute to improved care in the future.

## METHODS

As there was pre-existing literature the first step was to draw this together, to establish what is currently known about the topic. No existing systematic review was identified that had been completed or was underway. This study adopted systematic review methodology and, as the topic was about the lived experience, the research was essentially qualitative in nature so a meta-synthesis was undertaken using a contextualist approach. This approach acknowledges that multiple realities may be experienced, but it is still possible to identify a common underlying truth [16]. These realities are dependent on the context in which the person experiencing them is currently living and may change depending on their situation and experiences. A key aspect of this approach is an understanding of the researchers own background and biases. The primary author of the study is an experienced musculoskeletal physiotherapist who has experienced long-term knee problems. This creates a clear empathy with the participants in the various studies [16] The second author is a

health professional, with a long term interest in mental health, and so interested in psychosocial aspects of experiences.

The meta-synthesis was undertaken in three parts 1) a systematic search of the literature, 2) a critical appraisal of the relevant studies and 3) a meta-aggregation of the findings from the selected studies [17]. The findings of the study are reported in line with the ENTREQ guidelines [18].

## SEARCH STRATEGY

In order to perform a comprehensive pre-planned literature search the SPIDER approach [19] was used to produce a number of search terms from the study question (Table 1). The search was limited to publications between January 2006 and November 2016 and written in the English Language. The following databases were searched: CINAHL, AMED, Medline, Embase, PsycInfo and Web of Science. MeSH searches were also completed on CINAHL and Medline but these did not identify any additional papers. Citation searching of the selected studies identified no additional studies.

The searches identified a total of 358 papers. Once duplicates had been excluded, 90 papers remained; their titles were examined to check for relevance. Papers were excluded if they did not clearly meet the criteria in the SPIDER (Table 1). The main reasons for exclusion were studies that focussed on patients' experiences, or perceptions, of surgery, of returning to sport, or attitudes to other aspects of care (medication, exercises, self-management). The number of relevant papers was 39 (Figure 1). The abstracts were read in detail and a further 25 papers excluded as they did not meet the criteria set out in Table 1. The full text of the remaining papers

(n=14) were read and five further papers excluded as they focussed on attitudes towards surgery rather than the experience of living with knee pain. Nine papers met the full inclusion criteria and were deemed relevant for this study so were included in the review [20–28].

## QUALITY ASSESSMENT

Each of the selected papers was reviewed independently by JW and KB using the Joanna Briggs Institute Qualitative Assessment and Review Instrument (QARI) checklist [17]; where disagreements occurred these were discussed. Recourse to a third reviewer was available but not needed. The appraisal scores are displayed in Table 2. It was agreed *a priori* that all papers would be included within the meta-synthesis. Quality assessment in qualitative research is a relatively new in healthcare [29], as such many older papers may fail to adhere to more recent guidelines. Since we are looking for the lived experience of people, this may be well presented despite methodological flaws. Overall the quality of the studies was poor, with none of the studies scoring yes for more than four out of the ten items on QARI.

The studies used a variety of qualitative methodologies to explore the experiences of people living with knee pain. Whilst all of these were appropriate there was a lack of clear definition regarding the research methodology in most of the studies (the exception being the two papers by Mackay et al [24,25]). The lack of a clear theoretical standpoint creates difficulties when trying to interpret the findings of these studies [30]. The methods of data collection also varied. Most of the included studies used interviews, as would be expected to learn about the lived experience, but a survey, diaries and focus groups were also used (Table 4). The methods of data

analysis varied across the studies with narrative analysis [22,23,28], content analysis [24–26] and grounded theory [27] all being used. Particular concerns were raised over the recruitment strategies of a number of studies this is because participants were recruited from orthopaedic clinics whilst awaiting surgical procedures [21,26,27]; participants may have felt obliged to participate.

## Meta-Aggregation Process

In order to gain a true reflection of the researchers findings across the included studies a meta-aggregation process was used [17]. This approach seeks to reduce the subjective nature of thematic synthesis, since all themes identified must be clearly supported by the original text [31]. This approach aims to provide common or "universal" findings which can then be used to guide policy and decision making [31]. This approach also seeks to reduce any biases which exist within the researchers.

Each of the papers was initially reviewed and themes extracted from the findings (or results) section of each study by JW. Each theme was reported and supported (where able) with a reference from the original text. Themes were then classified as Unequivocal, Credible or Unsupported [17,31]. These were then reviewed by the second author (KB) and discussed to identify categories which were supported by at least two sources. This provided the basis for creating synthesised findings from across the different studies (Table 3).

## Synthesis of Findings

The included studies primarily focussed on the experiences of living with knee osteoarthritis; one paper explored the long-term experience of living with Anterior Cruciate Reconstruction [20] and two others looked at self-reported knee pain [24,25]. The majority of the studies concerned themselves with people in the older

age range, which is expected with osteoarthritis, however three papers did engage with younger participants [20,24,25]. The studies were multinational in origin, with studies from the UK (n=3) [22,23,28], Canada (n=3) [24,25,27], Australia [20], Sweden [21], and Taiwan [26]. The characteristics of the studies are shown in Table 4; it is noted that the studies by MacKay et al [24,25] and Ong & Jinks [22,23,28] used the same data sets for each of the studies with a different emphasis in the analysis of each study.

## Thematic Synthesis

The initial meta-aggregation process identified 55 findings across the nine papers. Of these findings 33 were considered to be unequivocal, 15 credible and seven unsupported. These findings were aggregated into ten categories, which produced two synthesised findings. The two synthesised findings were knee pain affects every aspect of life, and the search for the best way forward (Figure 2). The two synthesised findings were then assessed using the CONQUAL system [32] and were rated of very low quality.

## Knee Pain Affects Every Aspect of Life

Seven categories—emotional distress, change in relationships, lack of trust, increased awareness, coping strategies, loss of physical ability, regret and reflections—indicated that knee pain affects every aspect of life (Table 3). This finding is synthesised as: ‘Knee pain redefines what people are able to do, who they do it with and how they do it. Pain, fear and anxiety about the knees’ ability to function leads to reduced and/or adapted activity, and contemplation about lost ability and the emotional distress this can cause.’

In terms of what people are able to do participants reported their emotional distress as a feeling of depression, the loss of joy gained, and anger felt, at not being able to do things, and the overwhelming concern over what may happen in the future. Equally the impact of who they can do things with was captured in the category change in relationships, which identified the loss of social relationships due to knee pain stopping their normal activities; some reported that this led to social isolation and changes in their friends to those they felt better understood their condition.

The category coping strategies captured how they were able to do things. People reported difficulties in finding ways to manage their knee pain; this included discussions on returning to sport or finding alternative options to this. They also discussed the length of time it took to adapt to this new reality and the role medication played in this.

The pain, fear and anxiety felt by many respondents was identified across two categories: lack of trust in the knee and an increased awareness of the knee. The lack of trust led to the need to moderate activities and situations because participants did not feel their knee could be trusted not to fail on them. The increased awareness was reported as a feeling of wariness related to its ability to function correctly. This led to the reduced and adapted activity which was often identified as a loss of physical ability. Many reflected on the loss of function and their need to rely upon others to help with tasks which had once been simple. They also identified that many tasks were now considered impossible or needed to be adapted to continue.

The reflection of, and contemplation on, these changes was summarised in the final category: regret and reflections. People identified how their knee pain changed how they viewed themselves and their self-image, they reflected on how choices made in

earlier life may have influenced their pain and what they might have done differently given the chance

## Searching for the Best Way Forward

Four categories—gaining knowledge from friends, gaining knowledge from professionals, causes of knee pain, and pain and its' management—identified that many participants spent time searching for the best way forward (Table 3). This finding was synthesised as: 'People use a variety of traditional and non-traditional sources to find out about their pain and how to manage it. But often rely on their own judgement and knowledge to decide what is best for them'.

In terms of the traditional sources of knowledge people reported gaining knowledge from a variety of healthcare professionals, primarily this involved doctors and pharmacists. However a number identified their reluctance to access professional advice as they did not feel there was anything which could be done. As a result many turned to non-traditional sources of information with many seeking knowledge and management strategies from friends and acquaintances as well as the internet and written sources.

Many also sought to understand the causes of their knee pain with a wide variety of reasons identified such as overuse, injuries, diet and genetic makeup. They also sought information about pain and its' management. People discussed how they tried to manage their knee pain, what they felt affected it and how they were constantly looking for better ways to manage their pain. Some also discussed their reluctance to take traditional pain relief or to follow advice from professionals.

## Discussion

To the best of our knowledge, based on extensive searching and consulting experts in the field, this is the first review to bring together the existing qualitative literature that explores the experience of living with knee pain. The critical appraisal in the quality assessment identified considerable limitations within the methodological rigour of the studies; this is reinforced by the very low CONQUAL scores. The poor methodological quality of these studies highlighted the need for quality evidence in this area.

## Living with Knee Pain

This review has clearly identified the considerable effects knee pain has on every aspect of peoples' lives. This did not seem to vary according to the age of the participants; all groups reported disruption to all aspects of their life. Whilst some participants accepted this as a part of normal aging, many struggled to accept this change in their lifestyle. The disconnect between the societal expectations of remaining active as you enter advanced years was difficult for many participants to reconcile with the reality they were experiencing. This change in self-awareness whilst peers continued on 'a normal path' has been shown to have further negative impacts on self-perception [33]; several participants reported feeling isolated from previous friendship groups due to changes in their physical ability. In other conditions, i.e. Chronic Obstructive Pulmonary Disease, decreased physical activity has been shown to be progressive and associated with increased disease severity [34]. If this phenomenon is observed with knee pain, the reduction in social interaction with peers could have dramatic effect on overall health and wellbeing [35], and, combined with the emotional and physical impacts reported by the participants, presents a bleak picture of life living with knee pain.

## Searching for the Best Way Forward

A common thread throughout most of the studies was the participants' search for information about their condition. This included information about causes, disease progression, treatment and self-management. Many preferred to seek information from friends, family and online resources. Whilst this is a growing trend [36], many participants still turned to professionals for a confirmatory diagnosis or when symptoms became unbearable. This pattern is reported across all of the studies and does not seem to be dependent on context from the perspective of geographical location or healthcare system. A concerning observation was the view that the only option that could be offered was that of surgery, with no worthwhile treatment options available. This contradicts the current evidence base for knee osteoarthritis. Physiotherapy has been shown to be effective in terms of cost, pain relief and quality of life improvements [6]. The ESCAPE-pain programme in the UK has pioneered the use of combined education and exercise in the management of knee osteoarthritis [5]; this approach has shown excellent results both clinically and in patients' understanding of their condition [37]. Whilst this approach is now firmly embedded in physiotherapy practice, there is a suggestion that the key role of exercise and education is still not universal among primary care providers [38]. As primary care is generally the first point of contact for people with knee pain this may suggest a widespread lack of patient education provided throughout primary care irrespective of location.

## Implications for research

In terms of future research, methodological rigour is an important consideration. The studies in this study scored poorly on the QARI scoring. There were particular

concerns over the methodological rigour and theoretical underpinnings of the studies. Although most of the included studies used a variety of data collection methods were used. This, combined, with the lack of methodological rigour show the nascent state of qualitative research in physiotherapy. This emphasises the importance of all researchers undertaking qualitative research documenting the theory underpinning and methodology used in their study. This would increase the transferability and credibility of the studies. Future research studies should focus on whether psychosocial interventions improve outcomes, and what constitutes effective information provision, for people with knee pain.

## Limitations

Whilst the meta-aggregation process ensured the researchers' assumptions did not influence the analysis it may have led to some unique findings being lost as they were only identified in a single instance. The findings may not be generalisable to all types of knee pain and age ranges due to the predominance of osteoarthritis within the studies. Only English language studies were included which may have limited the transferability of the results.

## Conclusion

People living with knee pain often struggle to adapt to the new reality of their condition. They report a variety of ways in which they do, or do not, cope with this new aspect of their life. Many also report a difficulty fully understanding their new reality and a lack of clear and concise information available to help with this.

## Acknowledgements

None.

## Ethical Approval

Ethical approval was not sought for this study because it is secondary research.

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## Conflicts of Interest

None.

**Systematic review registration number:** CRD42017070227

*Table 1: SPIDER outlining search terms and inclusion criteria*

| S (Sample) | PI (Phenomenon of Interest) | D (Design) | E (Evaluation) | R (Research type) |
|---|---|---|---|---|
| Knee Pain | Experience | Interview | | Qualitative |
| Anterior cruciate | Feeling | Focus group | | |
| ACL | Perception | | | |
| Patellofemoral | Response | | | |
| Tibiofemoral | | | | |

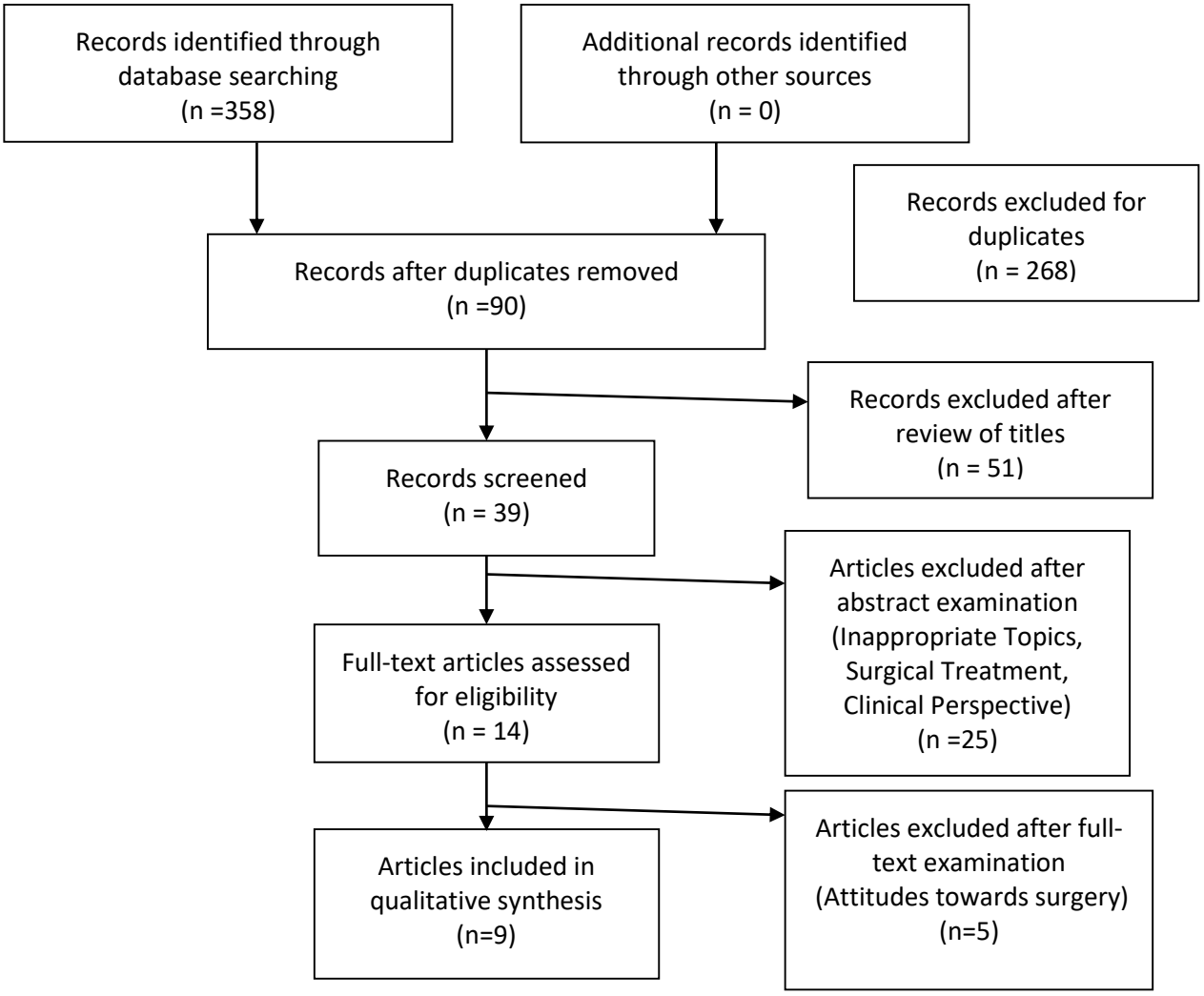


*Figure 1: PRISMA*[39] *flow chart of Review process.*

279

280 *Table 2: Summary of QARI scoring (Y= Yes, N = No, U = Unclear) for included studies*

| Study | Q1 | Q2 | Q3 | Q4 | Q5 | Q6 | Q7 | Q8 | Q9 | Q10 | Total Score |
|---|---|---|---|---|---|---|---|---|---|---|---|
| Fibay et al (2016) [20] | N | N | N | U | U | N | Y | Y | Y | Y | 4/10 |
| Hall et al (2008) [27] | N | N | N | N | N | N | N | Y | Y | N | 2/10 |
| Nyvang et al (2016) [21] | N | N | N | N | U | N | N | Y | Y | Y | 3/10 |
| Kao & Tsai (2012) [26] | N | N | N | N | N | N | N | Y | Y | Y | 3/10 |
| Jinks et al (2007) [22] | N | N | U | U | U | N | N | Y | Y | U | 2/10 |
| Mackay et al (2016) [24] | Y | Y | N | Y | U | N | N | U | Y | Y | 5/10 |
| Mackay et al (2014) [25] | Y | Y | N | Y | U | N | N | U | Y | Y | 5/10 |
| Ong et al (2011) [23] | N | N | N | N | N | N | N | Y | Y | U | 2/10 |
| Ong & Jinks (2006) [28] | U | N | N | N | N | N | N | N | Y | N | 1/10 |
| Question Total | 20% | 20% | 0% | 20% | 0% | 0% | 10% | 60% | 100% | 50% | |

Q1 = Is there congruity between the stated philosophical perspective and the research methodology?; Q2 = Is there congruity between the research methodology and the research question or objectives?; Q3 = Is there congruity between the research methodology and the methods used to collect data?; Q4 = Is there congruity between the research methodology and the representation and analysis of data?; Q5 = Is there congruity between the research methodology and the interpretation of results?; Q6 = Is there a statement locating the researcher culturally or theoretically?; Q7 = Is the influence of the researcher on the research, and vice-versa, addressed?; Q8 = Are participants, and their voices, adequately represented?; Q9 = Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?; Q10 = Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?

281

*Table 3: Synthesised findings from the included studies*

| Synthesised Findings | Categories | Author | Finding | Supporting quote | Page No: | Plausibility |
|---|---|---|---|---|---|---|
| **Knee pain affects every aspect of life.** It redefines what people are able to do, who they do it with and how they do it. Pain, fear and anxiety about the knees ability to function leads to reduced and/or adapted activity, | Emotional Distress | Hall et al (2008) | Emotional well-being | Depressed. Depressed. Very depressed. I mean, there have been times when I've sat down and had a good cry'' | 175 | Unequivocal |
| | | Nyvang (2016) | Change from their earlier lives - Emotional distress | The pain takes away the joy of doing things. Because you don't get done what you imagined because it hurts too much, and then, (it) takes over and I get angry, and that doesn't help | 4 | Unequivocal |
| | | MacKay (2014) | Emotional disruption | I got quite depressed. Suddenly I was overwhelmed with this feeling of I'm only 60-whatever-I-was at the time. We're very long-lived in my family, oh my god, is this the beginning of the next 30 years? (Jean, age 65, focus group 1) | 5 | Unequivocal |
| | | | | | | |

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|---|---|---|---|---|---|---|
| and contemplation about lost ability and the emotional distress this can cause. | Change in relationships | Hall et al (2008) | Leisure/social activities. | Because of the loss of leisure activity, the participants reported a loss in social contact that had accompanied the activity (Orbell et al, 1998). ‘‘It wasn’t so much the dancing, it was a real social experience… so, I kind of miss that | 175 | Unequivocal |
| | | MacKay (2014) | Social disruption | “I have a couple of girlfriends, who were walking regularly, and then I really hurt my knee bad and then I couldn’t join them. I am socially isolated because of it” | 4 | Unequivocal |
| | | MacKay (2016) | Experience with symptoms | their symptoms made them feel older was through shifts in their social relationships. Some participants conveyed that they related more to older individuals with health problems. For example, one participant said, “I’ve had a couple of really good friends that have been there for me. And, I mean, they’re older people, so they have | 345 | credible |

| | | | | | | |
|---|---|---|---|---|---|---|
| | | | | their own health issues, so they understand a bit better | | |
| | | | | | | |
| | Lack of trust in Knee | Filbay et al (2016) | Fear of re-injury: Fear avoidance | At the moment, pretty much, nothing. I'm always a bit cagey still. I'm always, it's always in the back of my mind, watch your knee, watch your knee. | 108 | Unequivocal |
| | | MacKay (2014) | Lack of trust in knee | "I have that feeling too. If I was coming home and it was dark and somebody was following me down the street, could I peel out of here…? Could I trust my knees to do that? | 7 | Unequivocal |
| | | | | | | |
| | Increased Awareness | Filbay et al (2016) | Fear of re-injury: Fear avoidance | At the moment, pretty much, nothing. I'm always a bit cagey still. I'm always, it's always in the back of my mind, watch your knee, watch your knee. | 108 | Unequivocal |

| | | | | | | |
|---|---|---|---|---|---|---|
| | | MacKay (2014) | A new awareness | Some participants reported that their knee seemed to always be on their mind. One woman recounted: “It’s just that I am constantly aware, thinking twice with very activity… Everything now has now a new think to it” | 7 | Unequivocal |
| | | | | | | |
| | Coping strategies | Filbay et al (2016) | Physical activity preferences - strong preference for participation in competitive sports | I do love netball. I hate the gym. Absolutely hate it. It makes it pretty hard when you can’t play the sports that you love, which I don’t consider to really be exercise, and you’ve got to find alternatives to exercise which I can’t stand | 105 | Unequivocal |

| | | | | | | |
|---|---|---|---|---|---|---|
| | | Filbay et al (2016) | Physical activity preferences - preferred, enjoyed or were satisfied taking part in noncompetitive recreational exercise | Oh look I probably could have played, but to me that was a fairly major injury that had me off for a long time from doing exercise, and the exercise that I like doing (recreational exercise), and I said I didn't want to risk doing it a second time. | 105 | Unequivocal |
| | | Filbay et al (2016) | Early adaptation | I was quite happy to give up netball and touch football because I just was not going to go through that again and didn't want to do it again, and switched to cycling and running. | 107 | Unequivocal |

| | | | | | | |
|---|---|---|---|---|---|---|
| | | Filbay et al (2016) | Delayed adaptation | I was about 90 kilos, I was very, very overweight, and like I'm 53 kg now. I just started exercising again, and eating well. Since I lost weight, my knee has never locked again. I just decided one day that that was enough and I just started exercising. I've gone from what I feel like 10% quality of life, to 100% quality of life, for me, being active is everything. | 107 | credible |
| | | Nyvang (2016) | Coping with knee problems - Alleviating pain | No, I don't think it's any fun if I'm going out to play golf and I have to take painkillers and you don't have a proper focus either. No, that's also why I want to get rid of the painkillers. I don't take many pills, I only do it when nothing else works anymore | 5 | credible |
| | | | | | | |
| | Loss of physical ability | Hall et al (2008) | Loss of functional mobility and | ''I'm lucky to have a husband, you know, who's mostly retired. He can help with beds and all those kinds of things...he does a lot more of the shopping and, of course, this all comes with the | 174 | Unequivocal |

| | | | | | | |
|---|---|---|---|---|---|---|
| | | | the need for assistance | retirement too ... he drives me to the hairdresser sometimes and so on.'' (F 80) | | |
| | | Nyvang (2016) | Change from their earlier lives - Struggling through everyday life. | You always have to plan what you do now, I never had to do that before. If I wanted to go biking, wanted to go skiing, or wanted to do something else, I could do it whenever I wanted to, but I can't do that now. | 4 | credible |
| | | Nyvang (2016) | Coping with knee problems - Physical coping strategies. | I can't take long walks when I'm out walking, for example, because then I know that I will get pain, and especially if I walk in town where there's asphalt. That also affects (the knee), and it depends on what type of shoes I have on. Strangely enough, it's easier to walk in the woods, even though it's uneven, but it's soft. Otherwise, I | 5 | credible |

| | | | | | | |
|---|---|---|---|---|---|---|
| | | | | can't dance and sometimes I have to take the elevator instead of stairs. | | |
| | | MacKay (2014) | Physical disruption | "I ran almost seven days a week for a good ten years, pretty much 5k a day every day. And there's nothing more in the world that I like more than doing that… And to have it cut off like that…" | 4 | Unequivocal |
| | | | | | | |
| | Regret and reflections | MacKay (2014) | Altered sense of self | Men, in particular, recounted that they once felt 'strong' and 'capable', but knee symptoms made them feel less capable. For instance, Peter (age 57, focus group 1) stated: "All of sudden you start thinking, I can't do this anymore, and you extrapolate from the physical to the other things…You start to think that … you're not as good as you used to be | 6 | Unequivocal |

| | | | | | | |
|---|---|---|---|---|---|---|
| | | MacKay (2016) | Prevention of symptoms | "What should I have done done different? I think I would have stopped jogging. I would have gone more on a bike…It was nice at that time, but there is payback" | 345 | Unequivocal |
| | | Filbay et al (2016) | negative knee-related lifestyle modifications | You know, I'm disappointed that I didn't go back, and I'm disappointed that I swapped the lifestyle instead of keeping up with the sporting lifestyle. I went to a social lifestyle, and started putting the weight on, because now I'm at the stage where I've got too much weight. I've got worse knee issues. I'm not helping it by being overweight. It certainly made me change my lifestyle. | 106 | Unequivocal |
| | | | | | | |
| **Searching for the best way forward**. People use a variety of traditional and | Gaining knowledge from friends | Hall et al (2008) | Lay sources of knowledge: Acquaintances and friends. | *''My friend's mother has had it done, and...yes, she can do everything she used to do, she has no pain, and, no, she doesn't have a limp. And she doesn't have to walk with a stick either. She had hers just over a year, eighteen months about. So* | 176 | Unequivocal |

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| non-traditional sources to find out about their pain and how to manage it. But often rely on their own judgement and knowledge to decide what is best for them. | | | | *it's very helpful to talk to somebody who's had it done." (F 63)* | | |
| | | Kao and Tsai (2012) | Acquisition of strategies - Opinions of neighbours, relatives, and friends | Actually, before I visited the doctor, my friends and relatives told me that elders had to maintain bone health. So they ate "Viartril-s" (a kind of glucosamine hydrochloride) to maintain their own bone health. I thought that everybody took it so I bought it. I wanted to maintain my own bone health. | 1831 | Unequivocal |
| | | Kao and Tsai (2012) | *Acquisition of strategies - Illness information* | I looked for a lot of information. Seven years ago, we did not have the Internet, I bought some books to read and learned how to protect my joints. | 1831 | Unequivocal |
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| | Gaining knowledge from professionals | Hall et al (2008) | Sources of knowledge: Physicians. | Part: ''I just know that they take out my knee and put in the metal Teflon replacement.''<br>Int: ''Is that the information that [DOCTOR] gave you?'' | 176 | credible |

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| | | | | Part: ‘‘Well, he showed me the actual joint.’’<br>Int: ‘‘The actual joint? Okay. And did he go through sort of the process of how it’s going to be?’’<br>Part: ‘‘No.’’ | | |
| | | Kao and Tsai (2012) | *Acquisition of strategies - Advice of primary care providers* | I asked the pharmacist, and he proposed that I must eat food that is good for my cartilage. If I was in pain, I went to the clinic near my home to get an injection. The clinical doctor said that the fascia was inflamed. Sometimes he prescribed the antibiotic and analgesic medicine that reduced the pain | 1831 | Unequivocal |
| | | Kao and Tsai (2012) | *Search for confirmative diagnosis - Confirming diagnosis at* | when I couldn’t bear the pain any longer, my family members told me to go see a doctor. I visited the doctor in the neighboring public health center. The director explained to me that this condition starts at a time earlier than old age. You | 1832 | credible |

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| | | | *orthopedic clinics* | must go to the hospital to have the diagnosis confirmed. Then I registered as an orthopedic outpatient at a hospital. Only then did I know, after an X-ray examination, that this is degenerative arthritis. | | |
| | | Jinks et al (2007) | *Health care use* | "I haven't been to the doctors about it because I can't see any point, they can't operate and all they'll say is we'll give you ...I mean, we've got some fine doctors, so no, there's a limit to what they can do. Well, I mean, ...I don't even go to the hospital now. I mean, it's just, ...I take it that there's nothing you can do about it. I ...all I go to see him is ...well, I don't really go for anything bar my ... six monthly check-up. No, I never say anything. As I say, there's not a lot of point. All he could do is give me another painkiller and that's it | 6 | Unequivocal |
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| | Causes of knee pain | Kao and Tsai (2012) | *Causes - Excessive knee joint loading* | I worked in the service industry and at a hotel counter, I often climbed up and down stairs and walked back and forth. Sometimes I had to stand for a long time. Therefore the knee could be very painful, I thought possibly that was what increased the knee pain now | 1830 | Unequivocal |
| | | Kao and Tsai (2012) | *Causes - Injury or other disease* | I had high-level uric acid and gout for many years. Sometimes my feet hurt when I walked. So I supposed the causes of the knee discomfort were gout and high level uric acid that affected the knee joint | 1830 | Unequivocal |
| | | Kao and Tsai (2012) | *Causes - Unhealthy dietary habits* | I drank latte coffee every day. It was black coffee, but I always added fresh milk. I thought that this small amount was okay. But this combination created the calcareous loss and the initiation of osteoporosis like this | 1831 | Unequivocal |

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| | | Kao and Tsai (2012) | *Causes - Family genetic disease* | many people in my family had rheumatitis, including my father. Many of these rheumatic people couldn't walk. I thought that my own symptoms looked very much like my father's rheumatitis and that my knee joint ache was caused by rheumatitis | 1831 | Unequivocal |
| | | MacKay (2016) | Cause of symptoms | "What has happened is in some ways when you abuse or overuse it, there is a wear . . . in my case, I overused it more than a normal function which the body was supposed to do" | 344 | Unequivocal |
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| | Pain and its management | Kao and Tsai (2012) | *Acquisition of strategies - Traditional medical help* | When I was uncomfortable I went to ask the traditional Chinese doctor for massage. If this region had pain he would massage it. He used his hands to massage the same lumbar vertebrae and both sides of the pelvis | 1831 | Unequivocal |

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| | | Jinks et al (2007) | *Medicine use* | So she put me on a stronger Ibuprofen type of slow release which ...seems to help. She wanted me to have two a day, one in the morning and one at night, but I won't. I only have one in the morning. Sometimes I don't even have that cos like I say, I don't want to be stuck with tablets. I'm wary of side effects [...] You hear of the Ibuprofen type of thing can give you stomach bleed or anything. I don't want that, you know, or indigestions." (Shirley) The level of discussion with the GP or other health professionals about the pros and cons of taking NSAIDs did not appear to be high, and in the interviews people said that they tended to make their own decisions about dosage. This reflected findings from other studies that people try to take as little medication as possible. | 7 | Unequivocal |

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| | | Jinks (2007) | *Patterns and descriptions of need* | Most people talked about knee pain in relation to specific activities such as being still in one position for some time, going up and down stairs or walking. The qualitative data, therefore, underpins the survey results. "I mean, if I sit too long, that doesn't help either. But the worst part is if I'm asleep and my legs are bent and I haven't woke up, the pain, I can't tell you what it is like. I can not move it...and what I do is I grip both hands round the knee and try to force my leg straight and I break out in a hot sweat. All I can say is that it is a bony pain. I could shout out with the pain." (Heather) The level of pain ranged from what was described above as discomfort, to severe pain that stopped people from undertaking many of their normal daily activities. | 4 | Unequivocal |

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| | | Jinks et al (2007) | *Self care and home remedies* | *Everything that comes on the telly, I say...Oh, I'll try those, I'll try one of those, you know see how it works. Nothing really cures it but it does ease the pain."* | 8 | credible |

*Table 4: Study Characteristics*

| Authors<br>Year of<br>Publication | Aim | Methodology and Methods | Participants | Main themes and recommendations |
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| Filbay et al [20]<br>2016 | 1)How do people with knee symptoms describe their quality of life and experiences 5 to 20 years after ACLR?<br>2) What factors affect quality of life in people with knee symptoms 5 to 20 years following ACLR? | Methodology:<br>Not Stated<br><br>Methods:<br>Semi-structured Interviews | <u>Number of Participants:</u><br>17 (7 male, 10 female)<br><u>Recruitment source:</u><br>Previous cross-sectional study<br><u>Sampling Method:</u><br>Purposive<br><u>Age:</u><br>Mean = 36 (range 25-50)<br><u>Country</u>:<br>Australia | • Lifestyle Modification<br>• Adaptation and acceptance<br>• Fear of re-injury<br><br>**Recommendations**:<br>None |
| Hall et al [27]<br>2008 | To examine individuals' experiences living with OA of the knee and what their expectations | Methodology:<br>Not Stated | <u>Number of Participants:</u><br>15 (9 male, 6 female) | • 'Breakpoint'<br>• Seeking knowledge<br>• Expectations / goals |

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| | are of arthroplasty and physiotherapy. | Methods:<br>Semi-structured interviews | Recruitment source:<br>Orthopaedic clinic<br><br>Sampling Method:<br>Purposive/convenience<br><br>Age:<br>Mean = 67 (range 52-80)<br><br>Country:<br>Canada | • Perceptions of post-operative physiotherapy<br><br>**Recommendations:**<br>Post-operative education, use of local support groups to prevent social isolation, Implementation of preoperative exercise program. |
| Jinks et al [22]<br>2007 | To examine knee pain and disability as reported by individuals participating in a population survey. | Methodology:<br>Mixed-methods<br><br>Methods: | Number of Participants:<br>22 (for qualitative interviews),<br>(12 males, 10 female)<br>10 diaries<br>Recruitment source: | • Health care use<br>• Medicine use<br>• Selfcare and home remedies |

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| | To investigate subsequent health seeking-behaviour in order to understand the rationale behind peoples' decisions to seek or not seek health | Survey and Semi-structured interviews and diaries | GP database<br>Sampling Method:<br>Purposive sampling<br>Age:<br>Mean = 68 (range 53-85)<br>Country:<br>United Kingdom | **Recommendations:**<br>None |
| Kao & Tsai [26] 2012 | To explore the lived experiences of middle-aged adults with early knee OA in prediagnostic phase | Methodology:<br>Not stated<br><br>Methods:<br>Semi-structured interviews | Number of Participants:<br>17 (3 male, 14 female)<br><br>Recruitment source:<br>Orthopaedic clinics<br><br>Sampling Method:<br>Purposive<br><br>Age: | • Awareness<br>• Surmise of causes<br>• Acquisition of strategies<br>• Searching for confirmative diagnosis<br><br>**Recommendations:**<br>Improved education for patients, including lifestyle, activity, and self-management activities. |

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| | | | Mean = 49.6 (range 43-55)<br><br><u>Country:</u><br>Taiwan | |
| Mackay et al [25] 2014 | To explore the perceived consequences of knee symptoms on the lives of people aged 35–65 years who had diagnosed osteoarthritis (OA) or OA-like symptoms. | Methodology:<br>Unclear<br><br>Methods:<br>Focus Groups and Interviews | <u>Number of Participants:</u><br>51 (20 male, 31 female)<br><br><u>Recruitment source:</u><br>Advertisements in press and various locations.<br><br><u>Sampling Method:</u><br>Purposive<br><br><u>Age:</u><br>Median = 49 (range 37-65) | • Disrupted physical, social and emotional life<br>• Altered way of thinking about body and self<br><br>**Recommendations:**<br>Interventions are needed to help keep active. Greater awareness of emotional effects. |

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| | | | Country:<br>Canada | |
| Mackay et al [24]<br>2016 | To explore the meaning of knee symptoms to people ages 35–65 years, focusing on how people understood or perceived their knee symptoms. | Methodology:<br>Constructivist grounded theory<br><br>Methods:<br>Focus groups and Interviews | Number of Participants:<br>51 (20 male, 31 female)<br><br>Recruitment source:<br>Advertisements in press and various locations.<br><br>Sampling Method:<br>Purposive<br><br>Age:<br>Median = 49 (range 37-65)<br>Country:<br>Canada | • Knee symptoms are preventable<br>• Explanation of knee symptoms<br>• Experience with symptoms<br><br>**Recommendations:**<br>Research needed into preventative interventions. |

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| Nyvang et al [21]<br>2016 | To describe patients' experiences of living with knee OA when scheduled for surgery and further their expectations for future life after surgery. | Methodology:<br>Qualitative descriptive design<br><br>Methods:<br>Semi-structured interviews | <u>Number of Participants:</u><br>12 (5 males, 7 females)<br><u>Recruitment source:</u><br>Awaiting knee arthroplasty<br><u>Sampling Method:</u><br>Convenience<br><u>Age:</u><br>Median = 65.7 (range 47-77)<br><u>Country:</u><br>Sweden | • It's not just a knee, but a whole life<br>• Change from earlier lives<br>• Coping with knee problems<br>• Ultimate decision to undergo surgery<br><br>**Recommendations:**<br>Individualised approach to treatment and patients involved in decision making process. |
| Ong & Jinks [28]<br>2006 | To describe older people's everyday experience and context of living with knee pain and disability, and to explore the | Methodology:<br>Not stated<br><br>Methods:<br>Diary analysis | <u>Number of Participants:</u><br>10<br><u>Recruitment source:</u><br>Recruited from Jinks et al.<br><u>Sampling Method:</u> | • The cause of pain and its meaning<br>• Knee pain in the context of co-morbidity<br>• Consulting for knee pain |

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| | potential of open-format diaries in accessing these experiences. | | Unclear<br>Age:<br>Not reported<br>Country:<br>United Kingdom | **Recommendations:**<br>None |
| Ong et al [23]<br>2011 | To explore the meaning and enactment of self-management in everyday life and the hard work associated with devising and maintaining routine adaptive strategies | Methodology:<br>Not stated<br><br>Methods:<br>Semi-structured interviews and diaries | Number of Participants:<br>22 (9 male, 13 female)<br>Recruitment source:<br>Participants in larger study<br>Sampling Method:<br>Unclear<br>Age:<br>Not reported (only age categories)<br>Country:<br>United Kingdom | • Change and continuity: organic responses to the impact of pain<br>• Reflection and evaluation: self-management as planning work<br><br>**Recommendations:**<br>None |

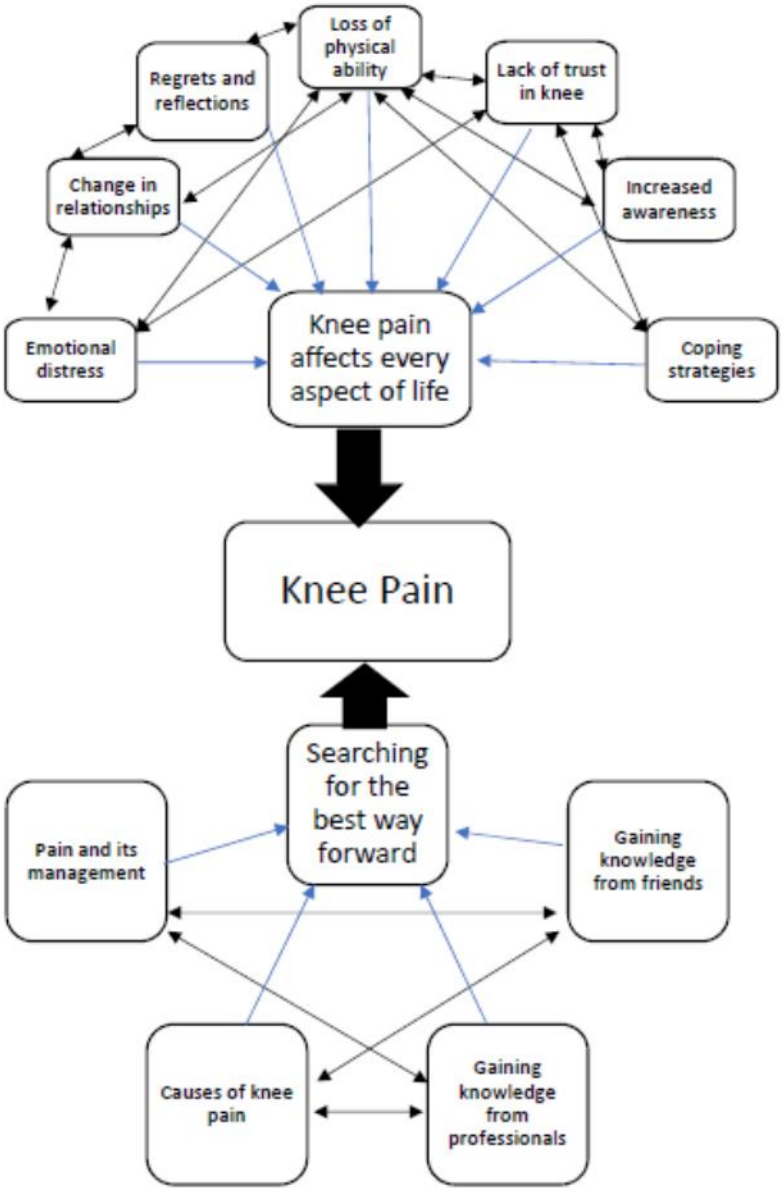


*Figure 2: Mind-map showing interaction between categories: Bi-directional black lines show interaction between categories. Uni-directional lines show the development of synthesised findings*

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